



Caring for Patients at the End of Life

Care of the Family When the Patient Is Dying

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Families shoulder many burdens during terminal illness. Their needs grow and change as their loved one's illness progresses. We describe specific physician behaviors that can assist families in coping with terminal illness. Early in serious illness, there are the emotional burdens of learning of the illness and coming to accept a terminal diagnosis, of giving up hope of cure. As terminal illness progresses, patients often need family members to help refocus hope despite the inevitability of death. Patients and families need support, guidance, and encouragement to begin planning for many decisions. Although emotional burdens are felt by most family members, families who choose to have their loved one die at home take on enormous direct caregiving burdens as well. They need information and supplies, including specific teaching of caregiving skills and logistic support. After the death of the loved one, family members have bereavement needs that require ongoing support.

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Most people do not endure a terminal illness alone. A family member or friend often accompanies the person along the entire trajectory of illness, from news that an illness may be life-threatening, to acceptance of the illness as terminal, through the final phases of the dying process, to the death itself. This may be a spouse, child or grandchild, some member of the extended biologic family, or, as in the lexicon of the AIDS [acquired immunodeficiency syndrome] community, a member of "the family of choice." For the purposes of this article, we have chosen the broadest possible definition of family: "Two or more people who share goals and values [and] have long-term commitments to one another" (*American Heritage Dictionary of the English Language*, 1992).

Recent literature details the tremendous burdens on families during serious illness. Families coping with serious illness shoulder substantial caregiving responsibilities.¹ They suffer considerable financial losses² and have increased rates of anxiety,³ depression, and chronic illness.⁴ Those caring for a loved one dying at home also experience a decline in physical and mental health.^{5,6} This evidence lends support to the idea that families, as much as patients, need to be cared for during a patient's terminal illness.

Families bear many burdens during terminal illness. Their needs grow and change as their loved one's illness progresses, from the need for emotional support as they come to accept a terminal diagnosis, to specific anticipatory preparation for the final stages of their loved one's dying. After a patient's death, the family becomes the de facto primary recipient of care and has needs

ranging from expressions of sympathy to referral for bereavement counseling.

The focus of this article is to guide physicians as they offer information, guidance, and support for family members of their dying patients.

News of a Serious Illness

Early in the course of a patient's serious illness, the long-term prognosis often is uncertain. Although death may be a possibility, some realistic hope of cure often continues to exist. During this initial phase, most medical efforts will focus on aggressive interventions aimed at curing the disease. This focus may divert the physician's attention away from both planning and the considerable comfort needs of both patient and family. The provision of adequate analgesia with opioids may be withheld because of a lack of a "terminal or hospice status."^{7,8} Families often suffer from increased levels of anxiety or depression, yet may not attend to their own needs because they are concentrating on the ill family member.⁴ Most families will face substantial financial losses or caregiving burdens.² Patients and families still pursuing active treatment with the hope of cure or prolongation of life, however, are usually ineligible for the comprehensive array of support services offered by hospice programs. They may be unprepared emotionally, as well.

As a patient's illness progresses, the prognosis worsens, and hope for cure diminishes. Considerable conflict may develop as various family members and the patient move at their own pace toward acceptance that the illness is terminal. Family members may have vastly different

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preferences as to the wisdom of continuing to focus on curative therapies. These conflicts can divert attention away from the increasing comfort needs of the patient. Such conflict may also prevent a timely discussion of the patient's wishes. At times, physicians will need to meet individually with family members to better understand the dynamics affecting decision making.

For some family members, the completion of advance directives and living wills may be seen as a recognition that the patient's illness is terminal and thus a step that they may not yet be ready to take. But excessive delay may produce a crisis situation in which a patient becomes incapacitated and the family must assume responsibility for clinical decisions in the absence of knowledge about the patient's preferences. The absence of planning often complicates an already difficult decision. Physicians play a vital role in helping patients and families to confront the possibility that death may occur.

Acceptance of Terminal Diagnosis

Coming to realize that a loved one's illness is terminal has been described as a "dawning acceptance."⁹ Brief statements by physicians such as "Things are not going well" or "The tumor seems to be growing again" may begin to be heard as evidence of the inevitability of death. Visible signs of physical decline in a loved one often aid this process. Progressively, physicians need to openly discuss the reality of the terminal condition. Physicians are often faced with a need for both diplomacy and openness. They may begin with an explanation of the course of the illness and of the need to change the focus of treatment efforts. With time and support, families usually begin to make the transition from the hope of cure to more narrow goals. They begin to focus on the comfort of their loved one and the quality of life. They may hope that another holiday can be spent together, that a loved one's pain will be controlled, or that a family reconciliation will occur.¹⁰

Families typically welcome this discussion because most will have begun to confront this outcome. Even when most family members have accepted a terminal diagnosis, however, one or two members may persist in the belief in a cure. Other professionals may be consulted to help families in severe conflict. Families may benefit from an ultimate acceptance of death and the resolution of these conflicts.¹¹

Family Needs During Terminal Illness

Family goals will change with the acceptance of terminal illness. Previously held dreams of cure will cede to more limited objectives: the desire for quality of life, to maximize comfort, and to reach certain milestones, birthdays, or anniversaries. Their needs will change as well, concomitant with changes in goals. Physician and other team member behaviors during the various stages of terminal illness can help—or hinder—families and the patient in achieving these goals.

Interviews with surviving family members suggest that some physician behaviors are particularly helpful to

TABLE 1.—Family Needs During a Loved One's Terminal Illness

Timely communication
Frequent and consistent communication
Gear communication to need
Encourage planning
Be aware of family conflict
Accommodate family's grief
Refocus hope
Remain available
Focus on patient's wishes
Attend to the comfort of the patient
Follow up with family after the death

family members during a loved one's terminal illness.^{9,11} Table 1 lists specific physician behaviors that families have identified as helpful.

Communication Should Be Timely

If patients and families are to make informed choices and provide mutual support, they need to be given information promptly and accurately. Family goals and choices may change radically in the face of a new prognosis. Postponing discussions of terminal illness or disease progression may only encourage false hopes and lead to inappropriate choices.¹²

At times patients may wish that their families not be informed of their illness. Although families may be understandably eager for news of their loved one's condition, physicians must respect a patient's right to privacy and obtain permission from patients before communicating with family members.

Communication Should Be Frequent and Consistent

In the emotional turmoil of a terminal illness, many things health care providers say will not be remembered. Despite repeated discussions, families may be much more confused than their physicians realize. Inconsistent information from different members of the health care team increases family confusion. Physicians can anticipate this need and be prepared to share information repeatedly with patients and their families, often answering the same questions two and three times.¹³ The health care team must communicate frequently among themselves as well to ensure that a consistent message is presented to families.

Communication Should Be Geared to Need

Initially families may be ready only for news of serious illness and the potential for death. Time to reflect may be needed before a meeting to discuss the patient's prognosis. As the illness progresses, families need to be informed of the anticipated course—for example, how long their loved one might live, what limitations he or she might have, or what activities can be expected to be maintained. At later stages, more detailed instruction as to the final stages of death may be necessary.

Encourage Planning

Decisions to limit life-sustaining treatments often have to be made near the end of a patient's terminal illness. If preferences have been openly discussed with a loved one before this period, then decision making by family members will be greatly facilitated. The completion of living wills and advance directives may now be more familiar and acceptable to families following their use in the widely publicized deaths of Richard Nixon and Jacqueline Kennedy Onassis.

Many decisions remain for families following a death. These include questions of organ donation, autopsy, funeral, and burial plans. Whereas patients and families often wish to avoid or delay discussing these issues, planning lifts a burden from family members, who usually find it easier to "stand by" a loved one's wishes than to feel they are expected to "decide for" their loved one.

Be Aware of Family Conflict

As mentioned previously, we define "family" as broadly as possible. Patients with diseases that carry a strong social stigma, such as AIDS, may not have had contact with their biologic families for many years. Indeed, they may wish that some family members not be informed of their diagnosis. Some patients may have several competing families, such as a new wife and biologic children, each of whom questions the legitimacy of the other. In other cases, family members may be estranged from the patient and each other. Others may be incapable of confronting their loved one's illness and choose to withdraw. Physicians need to maintain an awareness of these dynamics.

The stress of terminal illness may exacerbate longstanding family conflicts. Obviously, these conflicts cannot be resolved simply and easily. But if left unrecognized, they may seriously complicate family decision making. The intervention of a social worker or chaplain can be valuable at these times. At other times, involvement of the hospital ethics committee may be beneficial.¹⁴

Accommodate the Family's Grief

Grieving before a loved one's death is a normal and necessary part of accepting a terminal illness. Recognizing and legitimizing these feelings with simple expressions of sympathy, such as "It must be difficult to watch your husband decline" or "I'm sorry your wife is dying," will acknowledge and respect their grief and can help encourage healthy grieving. It is often appropriate to acknowledge the frustration of the limitations of medical care.

Communication Should Refocus Hope

Even when the hope of cure is past, physicians can help families find hope and meaning in the passage of their loved one's remaining days. Families may find hope in all aspects of dying: that a spouse can remain comfortable and independent for as long as possible or that they can spend a last Christmas with the spouse. Physicians

who adopt an attitude that equates death with failure or who inform families that "there is nothing left to do" only serve to remove that hope and prevent families from living fully until their loved one's death.

Remain Available

Families are in need of support and information throughout a loved one's terminal illness. Families fear that they will be unable to cope with their loved one's death, that symptoms will be uncontrollable, that death will be unmanageable, and that their wishes will not be heard. As the time of dying nears, it is tempting for physicians to withdraw, to feel as if their work is done, and that they have, in fact, failed. Yet this is a period of great emotional need, and the continued contact with a trusted physician can be of great solace.¹⁵

Focus on What the Patient Would Want

When a patient becomes incompetent, the burden of decision making will fall on members of the patient's family. Frequently decisions will be difficult, such as choosing to withdraw life support. Some families feel that their burden is increased when they are told that "the decision is yours." Advance directives and a durable power of attorney may give valuable direction and foundation for family decision making. If advance directives are unavailable, families can often identify and honor a patient's previous verbal directives. Discussions regarding treatment decisions are best focused on "what the patient would want."

The Doctrine of Substituted Judgment holds that a surrogate is assigned to carry out the wishes of an incapacitated person, not those of the surrogate's own preferences.¹⁶ Families may wish to discuss in advance who the best surrogate might be, recognizing that it may not be a spouse or biologic next of kin, but might be a partner, lover, or other long-time friend.¹⁷ Nevertheless, families should be encouraged to make decisions in consensus with and with the support and endorsement of the health care team so that no single person feels fully responsible for decision making.

Attend to the Comfort of the Patient

The greatest service a physician can provide to a family will often be skillful intervention in symptom control of a dying loved one. None of the growth and acceptance that characterize a "good death" are possible if patients and families are in constant crisis over uncontrolled suffering. A recent study documented the inadequacy of current pain management in terminal illness.^{18*} Therefore, the provision of adequate analgesia with opioids and attention to other aspects of comfort remain paramount as illness advances.

Caregiving and Dying at Home

Given a choice, most patients prefer to die at home.¹⁹ The home is generally a safe, comfortable, and familiar

*See N. MacDonald, MD, "Suffering and Dying in Cancer Patients—Research Frontiers in Controlling Confusion, Cachexia, and Dyspnea," on pages 278-286 of this issue.

place in which to die. For many families, caring for a dying loved one can be a wonderful opportunity for connection and healing and a demonstration of love and affection through daily acts of caregiving.

The physical and emotional burdens of caring for a dying loved one at home may be considerable, however, particularly when persons are expected to maintain other family and job responsibilities.² Physicians must be aware of these burdens and work with other health care professionals to aid families in obtaining adequate support for this effort.

Referral to a home hospice agency is helpful. Family caregivers have many needs that are best met before the final stages of illness. Timely referral provides the opportunity for necessary anticipatory education. Family caregivers need time to learn the myriad tasks required to provide optimal care. A multidisciplinary hospice team is particularly well suited to achieve this.

A nurse may visit and begin to instruct families on symptom recognition and appropriate interventions. Families learn to monitor a loved one's pain and adjust analgesic medications as needed. The nurse can teach personal care skills required when the dying person can no longer do self-care. The nurse can teach families what to expect during the final stages of dying. A physical therapist may visit and teach the family caregivers how to cope as the patient's functional abilities decline and can provide assistive devices as needed. Social workers may help with planning and assist families in adjusting to the changes in roles and family dynamics precipitated by terminal illness. A chaplain may be available to respond to spiritual needs.

Many crises may be successfully averted with appropriate planning. At times, however, despite the best efforts of all involved, a home caregiving situation may become untenable. The Medicare Hospice Act provides for admitting hospice patients to an institutional care setting if symptoms become uncontrollable. A five-day hospital stay benefit is also available with no justification for admission needed beyond that of providing respite for overburdened caregivers. Families may persist in struggling to maintain a loved one at home even as caregiving becomes unmanageable. These families can benefit from encouragement to relinquish the hope of a death at home without feeling that they have failed.

Callahan has written persuasively about the moral limits of our expectations for family caregivers.²⁰ Although death at home may fit our idealized version of a "good death" and may be the patient's strong desire, for many families this may not be realistic and may not be their preference.

Death in an Institutional Setting

Although more deaths are occurring at home, the preponderance of deaths in the United States still occur in an institutional setting. In these instances, physicians will often be responsible for communicating the news to the family. This role can be anxiety-provoking for many

house officers and physicians because little formal training exists in this area. We have previously published guidelines for physicians and established a curriculum for medical students entering residency training.²¹

When an in-hospital death can be anticipated, advance notification of family members may allow them to be present at the time of death. Many survivors who are unable to be present at their spouse's death express strongly their desire to have been present.²² If the attending physician or primary resident is not on call, families should be introduced to, or at least be notified of, the on-call physician's name. When death occurs, the physician should make a brief but unhurried examination to confirm the death and state plainly, "He (or she) has died." Jargon or euphemisms that may confuse survivors are best avoided. The physician should remain available after the death to answer questions. Providing a single, quiet room for grieving is critical. Often family members will wish to remain present with the deceased for some time following a death, and provisions should be made for this desire.

When a death is expected and families have agreed in advance, physicians may inform a family member or their designee over the phone. This designee may be a chaplain, friend, or neighbor who can go be with a surviving spouse or other family members who might otherwise be alone. A brief recounting of the final stages of life, "His heart began to weaken and finally stopped," followed by a concrete statement, "He has died," is recommended. An expression of sympathy, "I'm sorry," or reassurance, "His death was peaceful," is appropriate. Some time should be given for questions and expressions of grief, although when death is expected, these frequently are muted.

When death is unexpected, as may occur in 30% of patients,²² less planning is possible, survivors' needs are greater, and much more care needs to be taken. Notification by phone often does not meet family needs. Rather, the family should be given brief medical information, such as "Your husband was in a car accident and seriously injured," and the family should be invited to come to the hospital as a group. This provides time to gather other family or friends for support and to ponder the real possibility that death may have occurred.

Occasionally distance or other obstacles may prevent families from coming to the hospital without great effort, risk, or sacrifice. These families may need to be informed directly of the death. At other times family members may ask directly, "Is he dead?" In this case, they should also be told the truth: "Yes, he is." Most ask a less direct question, "Is she OK?" Here it is usually preferable to again encourage the family to come to the hospital, while pausing to listen for a more direct question about death.

At the hospital, the physician should sit with the family, briefly explain the circumstances leading up to the death, and directly state that death has occurred. Because the family is unprepared for the death, expressions of grief will usually be much more pronounced, and questions will be frequent and repetitious. Providing a quiet, undisturbed private place for families is all the more important. Physicians and other health care providers can

expect to spend a prolonged time answering these questions and providing support.

Direct viewing of the deceased helps families to accept the reality of death, and they should be offered the opportunity to see their loved one. Privacy in viewing their loved one is also important and may require moving the deceased. Viewing the deceased is often retained as a graphic memory. Therefore, any trauma to the body due to accidental death or resuscitative efforts should be surgically dressed or otherwise concealed. Endotracheal tubes, intravenous lines, and any signs of blood should be removed, giving the family a more peaceful memory of the death.

Bereavement

It is after a patient dies that the family becomes the primary focus of care; it is also a time of ongoing family needs. Research suggests that spouses are at increased risk of morbidity and mortality during bereavement.²³ Yet, it is precisely at this time that minimal if any contact with their loved one's health care providers occurs. In our interviews with bereaved spouses a year after their loved one's death, 50% reported no contact with the patient's physician following the patient's death. Expressions of sympathy, a follow-up card, or a phone call had been greatly appreciated. Spouses who had received a card usually saved it and showed it to our interviewer, expressing much gratitude.¹¹ As a result of this investigation, our institution has implemented a program of routine contact with grieving families following a patient's death.²⁴

Bereavement is uncomplicated in most situations. Many spouses, however, will be unprepared for the events of normal grieving. Physicians can assist grieving spouses by informing them that vivid dreams and tearful memories of the departed spouse may persist for several months and that a loss of interest in outside activities will likely persist for three to six months. Holidays, anniversaries, birthdays, and other special events may evoke particularly strong memories. Spouses should be encouraged to make special plans to be with family or other supportive persons during such times. Many may also take great comfort by joining a support group a few months after their spouse's death.

Some spouses are at high risk of complicated bereavement. Unexpected deaths, younger age, and previous psychiatric illness have all been linked with complicated or prolonged bereavement. Appropriate intervention in high-risk persons may prevent prolonged and complicated bereavement.²⁵ Clinicians need to maintain an awareness of this possibility and make appropriate referral when necessary.

Conclusion

Family needs change throughout terminal illness. Families need effective communication to help cope with

and accept a terminal diagnosis. As the hope of cure diminishes, families need encouragement to plan ahead, to begin to focus on comfort and quality of life in place of prolongation of life. In the final stages of dying, families need physicians to not withdraw, to remain available for emotional support, and to provide ongoing assistance in symptom control. Following a loved one's death, grieving families need ongoing support from health care providers.

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